

The Human Genome Organisation

22 June 1989

Mr. Nobuyuki Nakamura President, Tonen Company 1-1-1 Hitotsubashi, Chiyoda-ku Tokyo JAPAN

Dear Mr. Nakamura,

As you probably know, in the last few years there has been a world-wide wave of interest in undertaking a major research project to map and sequence completely the human genome. This is known as the human genome project and is the largest project ever undertaken in biology.

Plans for work on the project have come from several countries, including Japan and the United States. Realizing the importance of international collaboration in this effort to benefit mankind, a group of 42 scientists drawn from 17 countries banded together to establish HUGO (The Human Genome Organization).

Someone has referred to HUGO as a "U.N. for the human genome". It has as its objectives the coordination of research in mapping and sequencing, oversight of the maintenance and networking of databases, facilitation of exchange of biomaterials necessary for conducting the project, and provision of a forum for discussion of ethical, societal, legal and commercial aspects of the project.

HUGO is just about to start its activities, and for this reason it is urgently looking for funding. HUGO can be expected to achieve eventually a solid financial background, but currently its opportunities for financing are limited, especially relative to the strong and urgent demands for HUGO's quick and effective roles in the world. Activities such as initiating training courses, organizing meetings to help unify efforts in gene nomenclature and computerized data collection, and the overhead costs associated with starting HUGO have to date relied on early donations from colleagues and foundations who understand the objectives and importance of HUGO.

This letter is specifically asking Tonen's favorable consideration of financial support for HUGO. We are seeking funding for the important programs to implement the objectives outlined earlier. We feel that a very important, indeed urgent role for HUGO will be the conduct of an international biotechnical and bioscience training program to build up the manpower available for work in this area. There simply are not enough well trained scientists and technologists to conduct the work. We are very desirous of raising money soon for this aspect of the HUGO program. If desired, a crowned fund entitled "Tonen Fund for Training in Human Genome Research" or "Tonen Fund for Research in Molecular Biology," for example, could be established.

In concluding, I would like to indicate the legal status, the organizational structure, and the administrative arrangements for HUGO:

1. Hugo is incorporated in Geneva, Switzerland. Its administrative offices are being set up at 3 sites: the North American office is in Bethesda, MD; the European office is in London; and the Pacific office is in Osaka.

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Secretary: John Tooze, European Molecular Biology Organisation, Postfach 1022.40, D-6900 Heidelberg, West Germany

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- 2. The "supreme body" of HUGO is the membership (presently 219 in number). The executive body of HUGO is the Council consisting of the president, 3 vice-presidents, 5 previously elected members, and 9 members to be elected by the general membership at the next election in the fall of 1989.
- 3. Members are elected on the basis of merit in an annual election. The next election to membership will be conducted in the fall of 1989.
- 4. The officers of HUGO are President, Victor A. McKusick, Baltimore; Vice-presidents, Sir Walter Bodmer, London, Jean Dausset, Paris, and Kenichi Matsubura, Osaka; Secretary, John Tooze, Heidelberg; and Treasurer, George Cahill, Boston.

I am enclosing herewith the following materials:

- 1. VArticles 1-3 of the Articles of Association.
- 2. The Montreux statement. This is a statement of the objectives of HUGO as laid down at the initial meeting of the Founding Council in Montreux, Switzerland in September, 1988. With the statement is a list of members of the Founding Council.
- 3. √A list of the members of the Executive Committee which oversees the affairs of HUGO until after the election in the fall of 1989.
- 4. ✓ A reprint of an article in the New England Journal of Medicine (April 6, 1989).
- 5. A preprint of an article to appear in the scientific journal Genomics August 1989.

I would appreciate very much the opportunity to explore with you further the possibility of generous support to either the general programs of HUGO or to specific programs such as the international training program.

Very best regards,

Sincerely,

Victor A. McKusick, M.D.

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President, HUGO

Encl.